# Parent Partners – From a Seat at the Table to Setting the Agenda







#### **EHDI Conference 2020**



## Introductions



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# **Objectives**



# Identify three challenges of partnership



Identify opportunities in your state EHDI system



Identify three opportunities for change

# Background

### History

- The EAR Foundation of Arizona
- EHDI Coordinator
- Parent Support

### **HRSA Directives**

- Engage Parents
- Build Parent Leadership
- 25% of funding
- Next HRSA grant



# **Paradigm Shift**

#### How do we do this?



## Successes

#### **Increased parent commitment**

- Participating in grant writing
- Developing logic model, work plan and budget
- Systems development

#### Increased knowledge of the system

- Understanding the components of grant writing
- How our activities fit into the overall system
- A more global overview

#### **Increased collaborations**

- EHDI meetings
- Independent relationships with other agencies
- Negotiations with state agencies to change policy

## Challenges to Making the Change

#### Shift in Mindset – NOT THERE YET!

- Need to build trust both ways
- Getting invited to the table in order to help set the agenda
- EHDI partners not ready to hand over "control"
- Acknowledgement of the movement toward parent leadership and engagement

#### **Buy-in from EVERYONE**

- We are not JUST parents
- Parents are trained in other professions
- Parents receive training in unbiased support
- Ability to represent different viewpoints

#### Parents not feeling empowered

- Finding parents ready to LEAD
- Learning how to tell your story

## Opportunities in your EHDI System

#### **Build relationships**

- Meet other key players
- Attend meetings

#### **Join Committees**

 Every state has an Early Intervention committee, a Parent Training & Information center, Office Children with Special Health Care Needs

#### Meet your state legislators

- Know who represents you
- Keep track of current bills
- Make an appointment, bring your child

#### **EHDI Stakeholder Meetings**

- Meet your state EHDI coordinator
- Attend stakeholder meetings

# Make the Change

#### **Meet with your funders**

- Help write the grant, be an active participant
- Shape the MOU, don't just sign it

**Program design and implementation** 

- Input in anything that affects our kids
- Be involved
- Make Decisions

SHOW UP

- Be prepared
- Be engaged

# THANK YOU!

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